Innovative Clinical Trials Education & Outreach to African Americans

Stephanie J. Monroe, JD
Executive Director, African Americans Against Alzheimer’s

African American Network Against Alzheimer’s
Stand up. Speak out. Overcome.
Most Feared Diseases

- Alzheimer's: 54%
- Cancer: 26%
- Stroke: 10%
- Heart Disease: 6%

African American Network Against Alzheimer's
Forget Me Not Event Format

• Light reception
• 2 hour dramatic presentation
• Expert panel discussion with doctors, researchers, former AA research participants and Q&A
• Information tables with local research information, community resources and advocacy information
2015 Forget Me Not Attendees

• Primarily 65 and older
• 86% women
• Primarily African American (over 80%)
• 5 Cities (Atlanta, Tampa, Chicago, Indianapolis, and Houston) 3699 Registrants
Communication Channels: How We Reached Them

How they heard about the event

- Church
- Friend
- Flier
- Website
- Word of mouth
- Eventbrite
- Other

Atlanta
Chicago
Indianapolis
Houston
Communications Methods

Communication Opportunities

- Atlanta: Emails, Phone, Address
- Tampa: Emails, Phone, Address
- Chicago: Emails, Phone, Address
- Indianapolis: Emails, Phone, Address
- Houston: Emails, Phone, Address

African American Network Against Alzheimer’s
Stand up. Speak out. Overcome.
High Interest in Receiving Clinical Trials Information

Would like to learn more about clinical trials that may be available to them.

- Houston: 75%
- Indianapolis: 70%
- Chicago: 70%
- Tampa: 65%
- Atlanta: 65%
Willing to Join Online Brain Health Registry (BHR)

Willing to go to the Brain Health Registry (BHR) website, play games and provide health and other information

- Houston
- Indianapolis
- Chicago
- Tampa
- Atlanta

African American Network Against Alzheimer's
Stand up. Speak out. Overcome.
Willing to Advocate for Additional Alzheimer’s Research

Interested in advocacy actions they can take

- Houston
- Indianapolis
- Chicago
- Tampa
- Atlanta

African American Network Against Alzheimer’s
Stand up. Speak out. Overcome.
What We Learned

• If we are creative they will come

• They are interested in participating in research if asked

• They are interested in their brain health and will do online work if they have access

• They are hungry for information and answers from trusted, engaged, and ‘present’ institutions.
A New Opportunity

Minority Recruitment
Patient Engagement
Patient Voice in to Development of Trials
The National Alzheimer’s & Dementia Patient & Caregiver-Powered Research Network (AD PCPRN)
National AD PCPRN

Governed by: patients, caregivers, leaders of patient groups, directors of existing patient registries, CDRN/PPRN collaborators, and clinical studies representatives

Goals of PCPRN:
1) enroll an increasingly large number of subjects into this patient-centered network with a minority recruitment focus,
2) obtain self-reported information and measures of cognition at baseline and longitudinally,
3) screen & refer subjects for clinical trials, and
4) test a computable patient phenotype
B. SMITH SHARES HER STORY

Renowned model, actress and restaurateur B. Smith is partnering with the Brain Health Registry to help find cures faster for all people.

Learn More »

It’s safe, easy and free.

JOIN NOW
DONATE

Already a member? Log in here

New Approach for Speeding Recruitment for Clinical Trials -...
Thank You

www.AfricanAmericansAgainstAlzheimers.org